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ABSTRACT

This paper reports results of a series of intense post school follow-up interviews conducted during 1989-90 in southern Japan with mothers (and one father) of 12 young adults, who had been labeled severely or profoundly handicapped when in school. The interview process is described in some detail to underscore the importance of accommodating Japanese cultural expectations. Parents responded to specific questions on the California Follow Up Data Form and then were given an opportunity to ask questions or add other comments. Topics covered in the interviews included the former student's current employment status, past schooling experiences, use of free time, general feelings of life satisfaction, and future concerns. The most consistent and overwhelming concerns expressed by the parents were issues of public acceptance of their child's handicap. Most parents spoke with resignation about their child eventually living in one of the large government colonies. (DB)

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INTERVIEWS WITH MOTHERS OF FORMER SPECIAL EDUCATION STUDENTS IN JAPAN

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Special Education Through the Eyes of Parents in Japan

Parents play a significant role in the education of their children the world over. It is the parents who initiate the educational process with their young children and in the case of a child with a significant handicap it is the parents who continue the process long beyond the school years.

When the child has a severe handicap, parental involvement can be very intense throughout the child's school years and beyond, depending in part on cultural expectations. For example, P.L. 94-142 specifies that parents in the United States must take an active part in their handicapped child's education, including participation in education planning. This parental involvement begins at the time of the initial identificatior of an educationally significant handicap and continues for as long as the child receives special education services. In contrast, in Japan, the child's mother has little influence over the content of the educational program for her child, whether handicapped or not. Yet the child's mother is expected to be supportive of the school program and even accompany the child to school for as many years as needed, and to remain available for helping the teacher when needed.

Once school is completed little is known about the hopes and dreams of these parents and often, no one fully benefits from their many years of experience. These parents

who have been intensely involved in the school program and even have assisted in the identification and implementation of educational plans have gained valuable information. They have watched and taken part in the successes and failures and they have much to share. These parents have become experts on the topic of "what really made a difference," yet their wisdom is seldom tapped.

The Need for Post School Follow-Up

Education is guilty of the ostrich syndrome in neglecting to fully utilize parent input as a school effectiveness measure and a valuable source of information for school improvement. In addition school populations are becoming increasingly more diverse. Interviews with parents of former students not only reveal information about school effectiveness but when the interview is conducted in the home these contacts provide an opportunity to learn more about the child's culture.

Post school follow-up interviews as a means to examine the outcomes of school is not a new idea. Such studies have been reported in the literature (Matthews, 1919). In a review of the literature on post school follow-up, Burton, Faigin, Towner and Wojciehowski (1988) identified over 100 studies reporting the post school work, living and achievement status of a wide range of populations. Several studies reported results of parent interviews; however, almost no studies reported the results of parent interviews conducted in the home. Cultural considerations were not

emphasized in any of the follow-up studies. Given the rich ethnic diversity of schools in the United States, it is important to prioritize cultural implications when conducting post school status studies. Concerns, opinions, and expectations identified among parents from diverse cultural backgrounds can provide valuable information for enriching and improving services for all exceptional children.

The purpose of this paper is to report the results of a series of intense post school follow-up interviews conducted in southern Japan during the 1989-90 academic year. Families of twelve adults, who had been labeled severely or profoundly handicapped when they were in school, were interviewed by a Southern California university professor and a district school administrator. Both interviewers specialize in education of children of youth with handicaps and both participated in all twelve interviews. The interviews were conducted at ten homes and two special centers in Southern Japan. While these twelve interviews cannot provide significant data for conclusive implications, the findings and experiences of the authors do reveal relevant information for consideration in cross cultural educational interventions.

Recognizing and Responding to the Japanese Culture

The California Follow Up Data Form (Burton, Peterson, Towner & Wojciehowski, 1988) was used to structure the

content of the interviews. The faculty of Tohoku University Special Education translated the follow up data form under the direction of Dr. Masaki Nagafuchi. Interviews were arranged through coordination of Dr. Susumu Hachizuka of Kyushu University, Dr. Kenji Harizuka of the University of Occupational and Environmental Health in Kitakyushu, and Dr. Tsurukichi Takamatsu of the Kitakyushu Center for the Disabled. Two young Japanese mothers with degrees in linguistics interpreted the interviews. This group of professionals and parents served as project advisors and were invaluable to its success.

Several potential linguistic and cultural barriers were identified and overcome or diminished before beginning the interviews. The Japanese home is considered to be a sacred and private place, thus, it is not customary to entertain guests in the home. Homes in Japan are small, tidy and efficient, and the common perception among Japanese women is that Americans have huge luxurious houses. As this was the case, the Japanese mothers initially were reluctant to invite American visitors into their homes. Also, most people in Japan have had little or no experience with an English-speaking person, even though they may have studied English ten or more years in school.

In addition, people in Japan were found to be particularly proud and private about their lives, customarily handling their own problems quietly and effectively within the family. In a nation where high

achievement and service is expected, a handicapped child brings an element of shame to the family and is a curiosity to the community. The natural response is to keep the situation at a low profile. It was clear from the beginning that conducting these interviews would require careful establishment of a highly respectful and trusting atmosphere.

Finally, education is held in high esteem in Japan. It would be considered strange and uncomfortable to question the decisions of the teacher or to make other than praiseworthy comments about the school. Yet, here in Japan were two foreign educators asking parents to invite them into their homes for the purpose of discussing the prior education of their handicapped child. They would be asked to talk about the usefulness of the former school program in preparing their child for adult life and to share their concerns for the future. It was indeed a challenging undertaking.

Establishing Interviews in Japan

The first step in the research process was to translate and field test the California Follow Up Questionnaire. Upon advisement of the Japan Advisory Group, two questions that could not be conveyed to the Japanese families were revised and two additional questions were added. The Japanese version of the California Follow Up Questionnaire was then field tested with parents in Sendai, Japan.

Next, families in the Kitykyushu Perfecture of Japan who would participate in the Southern Japan study were identified. Research consultants Drs. Takamatsu and Harizuka compiled a random sample of school completers from two special centers and secured their agreement to participate. The two Japanese interpreters then contacted these parents and scheduled the interviews over a two week period in late Fall of the 1989-90 academic year.

A process for conducting the interviews was then finalized. During field testing at Tokoku University, Dr. Nagafuchi had accompanied one of the researchers and interpreted the questions and responses. A negative halo effect was detected when interpretation was provided by the famous doctor. The researchers recognized that in order to overcome this potential barrier and establish the optimal interview atmosphere, interviews should be as informal as possible. Also it was recognized that common experiences between the interpreter and the parents would further enhance the comfort level of the mothers and help create an atmosphere conducive to self disclosure.

The two Japanese women selected as interpreters for the twelve interviews were competent, warm and well educated, yet they were not practicing professionals. In addition, the interpreters were encouraged to bring one of their small children with them to the interviews. A young child's presence would serve as a transitionary tension breaker and

provide the interviewers with another opportunity to informally observe familial interactions in Japan.

The Interviews Begin

We were accompanied by the interpreter and her two and a half year old son, Fumio. Fumio served as an international goodwill ambassador, at times carrying on with antics to break the ice for the interviewers and momentarily divert attention away from the interviewee. His presence helped us bond quickly, and gave the Japanese and American women a common experience to share. Over time Fumio came to know the American interviewers well and was comfortable with his team. He offered an internationally understood "something else" which helped create the informal and open atmosphere we were seeking.

On entering the home we removed our shoes, with none of the grace of our Japanese interpreter. Our Japanese hostess shyly points to pairs of blue vinyl slippers we were to wear. A small gift was presented to the mother, who bowed, and finally accepted in polite humility. As we entered the living area we were introduced to the grandmother and the former special education student. Facial expressions are critically important, as we must rely on visual cues and simple phrases to establish this important relationship. When we stood, we towered over this petite mother in her late forties and well-preserved grandmother of seventy. When we sat on straw mats, we curled long legs under short

tables. The mother recognized our potential discomfort. We responded "Dai jobi" to express "I'm OK."

In each interview, we presented our "meishi" (business card). In this culture, the presentation of a meishi is not only an imperative business etiquette, it also opens the scene for formal interaction between people. Typically, meishi are exchanged among business and professional men who accept the card with a bow or nod and study it carefully before speaking. The mothers accepted our cards with delight and eagerness. The meishi evidences respect to the women, as well as serves as a starting point of conversation for the interpreter. The beginning of a trusting and open atmosphere for upcoming dialogue about various personal experiences was created in these first few moments.

We sipped the carefully brewed tea in respectful silence, studying the lovely cup and tea leaves. Light conversation between the mother and the interpreter continued as we offer occasional nods and smiles. Fumio provided a welcome distraction to our uncomfortable silences. When the tea was finished, our interpreter began by explaining the purpose and procedures for the interview. As the interpreter struggled with English phrases and turned to us for help, the mother and grandmother looked at her with admiration. The atmosphere gradually became comfortable and relaxed and there was evidence of a necessary rapport required for a successful personal interview (Gay, 1987). A mixture of discomfort, interest,

and compassion is shared by all, yet the potential value in the experience served as a great motivator to continue. Fumio needed another fish cake--everyone relaxed and attended to his needs.

Responses to the Interview Questions

The interviews inquired about governmental support for those who do not work. Parents confirmed that special funds are allocated by the Minister of Welfare, usually 50-60,000 yen or $405.00-480.00 monthly. The amount depends on the age of the child, the governmental ranking of the handicap severity and family need. Other financial support to families depends on the philosophy and commitments of local governments across the nation, and varies from free transportation and admission to local parks to assistance in establishing parent-operated workshops.

The twelve former students were 18-24 years old and all had completed or left school within the past four years. Each had been labeled as severely and/or "doubly" handicapped when they were in school. In eleven of the twelve cases the mother responded to the interview questions. One interview included the father's responses, and for most of the interviews the former student was present. All former students had attended special schools having experienced no integrative school activities.

Two former students were minimally employed at a special workshop which was owned and managed by parents of

adults with handicaps. One young man with intense physical disabilities and apparent strong intellectual abilities expressed a desire to work and talked about learning computer skills from his older brother. None of these young adults had experienced vocational training in school. One former student had received minimal instruction in typing in school and another had been "introduced" to a calculator.

Questions regarding the past school life revealed that arts and crafts comprised the school training in recreation/leisure skills. Domestic skills were similar, although one former student did report that twice a year he practiced washing and cooking rice at school. Six of the twelve parents felt domestic training would have been useful and two mentioned that the teacher worked with their child on self-feeding skills. For the most part domestic training, including toilet training, was considered a mother's responsibility, and most of the mothers had fed and toileted their son or daughter daily at school for many years.

In response to a question about use of free time, twelve of the former students enjoyed television and music. One parent spoke of walks as a favorite free time activity of her son. All leisure time activities were family and home oriented, and none of the former students spoke of spending time with a friend or nonpaid companion.

The last section of the interview was devoted to questions about general feelings of life satisfaction and

present and future concerns. On a 1 (very happy) to 5 (not happy at all) scale, seven parents rated their children as 2 (fairly happy), one as 1 (very happy) and the other five fell in the 3 (happy now and then) and 4 (not very happy) category. When asked about present concerns or problems, former students or parents shared specific examples of need such as "an adaptor for the computer"; "to position myself so I can study"; "to overcome transportation barriers in the community"; "to be comfortable or free from pain"; and "not to be depressed or bored." The most consistent and overwhelming concerns expressed by the parents were around issues of public acceptance of their child's handicap.

What about the Future...

One of the most moving aspects of the interviews came with the last question: "In terms of the future what are the most important things that you think about?"; "What will happen to my child when I am gone?"; "What kind of care will he really be given?'; "How can I make such hard choices about the future when she needs me so much?"; "What can I do when grandmother is gone?"; and, "Often I think about this and worry everyday." For the interviewers, this was the question that consistently brought tears - uncomfortable tears. Frequently an hour was spent in deep conversation about the child and future circumstances and opportunities.

When discussing the future, most of the mothers spoke with resignation about their child eventually living in one of the large governmental colonies. One mother responded,

"That's why he's living at the colony part-time now, so he can get accustomed before he goes there full-time." She reported that she cried when she left her son at the colony for the first time.

Another mother responded that her daughter is presently living at home, but she thinks that in four or five years she will need to live at the colony. She is an only child and has no one else to take care of her in the future. This mother also noted that she doesn't feel it is fair to expect a sibling to do the caretaking and knowingly shared that caring for her daughter is a full-time responsibility.

Several mothers spoke sadly of the fact that people stare at their child when they go out in the community. "Even after all of these years it still hurts." They consistently expressed worries about how people might treat their child if they were not present to protect their needs and feelings.

When questioned about the future, one mother responded that her son currently comes home from the colony for one week each month, but when she can no longer physically lift or position him she knows his life will have to revolve around life in a colony. She is looking ahead and has asked his younger brother and sister to promise to visit him at least four times a year, hoping they will be able to go more often. In response to the same question, another mother said that she will care for her son as long as she is physically able and at the same time she knows that it's

important to start thinking about the future. She is considering entering her son in a colony in the future and worries about space availability. According to this mother, some colonies are already impacted, with long waiting lists.

One mother spoke of specific plans to have her son living in the colony of handicapped persons by the time he is 30. With tears in her eyes she explained that this will be difficult. To help prepare her son for the future she has begun to invite handicapped people into her home so he will be more prepared for an adult handicapped environment. This same mother also expressed concern that her son's functioning level is below the entrance requirements to qualify for a colony. She, along with several other mothers, asked if there were also long waiting lists to get into colonies in the United States.

Several of the mothers agreed that thinking about the future brought sad feelings because there is no way that their child will ever be able to get a job. This was particularly a concern for mothers of young men. In the Japanese culture the life of a man is centered around work, with little time for leisure or family life. Success on the job, whether as a homemaker or a businessman, is a National expectation in Japan. This concept prompted several mothers to express sadly that, their child was of no value to the society. There was a universal belief expressed by each of the interviewees that a handicapped adult would not be

accepted in the workplace and would in fact be a deterrent to productivity.

In Closing...

There were many comments that were difficult for the Japanese parents to reveal in an interview situation. Yet, because of the uniqueness and high interest in the topic, and the tone established during the interviews, the parents were sincere and responded in apparent honesty. The interviews were conducted in two phases. First, the American visitors asked the parents to respond to specific questions on the California Follow Up Data Form. Then at the end of each interview the Japanese parents had an opportunity to ask questions or add other comments. Openness and honesty was especially apparent here and the conversation frequently continued long after the formal interview was finished. Whether seated on tatami mats on the floor of a home or on a folding chair at a table in a special center, the human exchange was powerful.

A sense of universality of the experiences was created between the mothers in Japan and two parents from the United States. Regardless of ethnic or economic background, this common experience transcended among many other cultural motifs and was an impressive learning experience for everyone involved.

The study was finished for the time being and there were many invitations to return. We left the lovely Japanese mothers and villages to return to our own families

and to resume our work with families and children in America. These impressions were lasting ones and continue to influence expectations and interactions of the researchers. Unforgettable are the memories of the families with handicapped children visited during those initial interviews in Japan.

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